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The Art and Science of Integrating Undoing Racism with CBPR: Challenges of Pursuing NIH Funding to Investigate Cancer Care and Racial Equity

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ABSTRACT *In this nation, the unequal burden of disease among People of Color has been well documented. One starting point to eliminating health disparities is recognizing the existence of inequities in health care delivery and identifying the complexities of how institutional racism may operate within the health care system. In this paper, we explore the integration of community-based participatory research (CBPR) principles with an Undoing Racism process to conceptualize, design, apply for, and secure National Institutes of Health (NIH) funding to investigate the complexities of racial equity in the system of breast cancer care. Additionally, we describe the sequence of activities and "necessary conflicts" managed by our Health Disparities Collaborative to design and submit an application for NIH funding. This process of integrating CBPR principles with anti-racist community organizing presented unique challenges that were negotiated only by creating a strong foundation of trusting relationships that viewed conflict as being necessary. The process of developing a successful NIH grant proposal illustrated a variety of important lessons associated with the concepts of cultural humility and cultural safety. For successfully conducting CBPR, major challenges have included: assembling and mobilizing a partnership; the difficulty of establishing a shared vision and purpose for the group; the problem of maintaining trust; and the willingness to address differences in institutional cultures. Expectation, acceptance and negotiation of conflict were essential in the process of developing, preparing and submitting our NIH application. Central to negotiating these and other challenges has been the utilization of a CBPR approach.*

KEYWORDS *Breast cancer, Community-based participatory research, Health disparities, Institutional racism.*

THE PERSISTENCE OF RACIAL DISPARITIES IN HEALTHCARE

A number of recently published studies have illustrated that African Americans, Hispanic/Latinos, and Native Americans receive a lower quality of healthcare

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and are less likely to receive routine medical procedures than Whites.[1,2] An Institute of Medicine report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*, reviewed a national sample of over 100 studies from a ten-year period and found significant and pervasive racial and ethnic healthcare disparities, defined as differences in the quality of healthcare that "were not due to access-related factors or clinical needs, preferences, and appropriateness of intervention."[2] Similar disparities have been identified regarding breast cancer and breast cancer treatment, which is the focus of our partnership's research effort.[3,4]

INSTITUTIONAL RACISM IN HEALTHCARE DISPARITIES

One factor that is rarely explored with regard to disparities in health and healthcare is the role of institutional racism. In the past, consistent findings of healthcare disparities have been explained by stereotyping, discrimination, and time pressure, which all occur in the context of institutional racism.[5] While there may be multiple approaches to addressing institutional racism, community organizing as an approach has been used to create change in a variety of organizations and systems, such as healthcare. This type of organizing requires building trusting relationships that are grounded in a common analysis of power and collective action for social change.[6]

Because such issues are not easily identified by standard research parameters, it is necessary to involve community members in the exploration of why health disparities persist. Building on such principles of developing trusting and equitable relationships, collaboration, and diverse areas of expertise, academic researchers have recognized the need to develop working relationships with community members to address health problems. This approach, community-based participatory research (CBPR), requires researchers to relinquish their role as the "expert" and emphasizes co-learning with community members as full partners in the research process.[7] Though CBPR shares many of the same guiding principles as community organizing, few examples exist which integrate CBPR with anti-racist community organizing efforts to address health and healthcare disparities.

In this paper, we explore our 18 month process of integrating CBPR principles with an Undoing Racism process that has community organizing as one of its key principles. This organizing effort led to our ability to conceptualize, apply for, and receive National Institutes of Health (NIH) funding to investigate potential disparities in the delivery of breast cancer care. While we will briefly discuss the background of our community-academic partnership, the primary focus of this paper will center upon the dynamics and challenges of preparing and writing an NIH proposal using a CBPR approach.

BACKGROUND AND OVERVIEW OF THE CANCER CARE AND RACIAL EQUITY STUDY (CCARES)

The initial impetus for this collaborative effort to address healthcare disparities came from the leadership of The Partnership Project and the University of North Carolina (UNC) Program on Ethnicity, Culture, and Health Outcomes (ECHO) whose mission is to improve the health of North Carolina communities by eliminating racial and ethnic health disparities through multidisciplinary and culturally sensitive research, education and training. The Partnership Project, founded in 1997,

employs the conceptual framework for undoing racism, which integrates community organizing principles with an understanding of institutional and structural racism. The Partnership Project and The People's Institute for Survival and Beyond are part of a national and international anti-racist and multi-cultural movement of community organizers who work for social justice and change. The Partnership Project and the UNC ECHO program began working together in September 2003 to develop a research proposal to address healthcare disparities due to race. This work was accomplished with a planning grant from a local community foundation to the Partnership Project with a subcontract to UNC. The planning period extended from September 2003 to May 2005. During that time, the following activities were completed: four months were spent identifying and recruiting research partners, community representatives and professionals from the private and public healthcare sectors, who committed to six months of completing Undoing Racism training, to understand and agree on the language to define the concepts of institutional racism, White organizational culture, and internalized racial oppression. Eight months were spent designing an exploratory CBPR study to generate hypotheses about institutional variables within local healthcare systems that contribute to racial disparities in breast cancer mortality. In May 2005, the UNC School of Public Health and The Partnership Project submitted the Cancer Care and Racial Equity Study (CCARES) proposal to the National Cancer Institute in response to the NIH Program Announcement, *Community Participation in Research*.

September–December 2003: Identifying and Recruiting Potential Partners

The Partnership Project interviewed 54 individuals and invited 12 medical/health professionals and 23 community members to join a collaboration of diverse individuals to address health disparities. This group became the Health Disparities Collaborative and it was deemed essential to strengthen the community membership to balance the authority that research and medical/health professionals often bring to any process. Although no criterion was set, the Health Disparities Collaborative was envisioned to be a group with the capacity to (1) think about the long-term interests of the community, (2) consider many perspectives, (3) learn the history and culture of healthcare, (4) commit to the eighteen month process, (5) understand the social/political analysis of racism presented in the training and be able to apply that understanding to create change, and (6) represent both traditional and non-traditional sources of power. The charge of the Health Disparities Collaborative was to work with the research team from UNC and The Partnership Project to identify the institutional variables hypothesized to be the risk factors in healthcare for African Americans locally and to design research to test these hypotheses.

January–June 2004: The Undoing Racism Training and Process

During the next six months, the membership of the Collaborative participated in five educational and five discussion sessions. These sessions were designed to enable individuals to share an analysis of institutional racism. The sessions began with a two and a half day of Undoing Racism training presented by The People's Institute for Survival and Beyond.[8] This training focused on understanding the history and institutional nature of racism and began providing the Collaborative with a common analysis and language from which to work. Four additional educational

sessions and five discussion sessions were held to train all members in understanding key elements of institutional culture and institutional racism and to review the latest research on racial and ethnic disparities in healthcare. All of The Partnership Project's efforts were framed around the need to organize groups to develop a movement for collective action and change and to nurture the Collaborative's exploration of how institutional racism impacts health and healthcare. It is important to note that at this crucial juncture, the Collaborative lost three members (one academic and two medical/health professionals), who were replaced with individuals recruited by UNC and The Partnership Project that completed the Undoing Racism training at a later time.

July 2004–May 2005: The CBPR Approach to Developing the Cancer Care and Racial Equity Study (CCARES) Proposal

The CBPR process for developing and submitting our grant proposal to the National Cancer Institute within NIH spanned eight months from July 2004–May 2005. To launch the multiple phases of this challenging process, the Collaborative met to: (1) complete a workshop on CBPR principles and approach, led by UNC partners; (2) sign a Full Value Contract, which was crafted through consensus to indicate commitment to the Collaborative's guiding principles; and (3) agree on a timeline and structure for responding to the NIH Program Announcement and associated deadlines. The Collaborative decided which members would serve on the following five subgroups, each responsible for a key component of the grant writing process: Research Question, Methods, Analysis and Dissemination, Proposal Reading, and Budget. Each subgroup was structured to include at least one academic partner from UNC, at least one medical/health professional partner, and multiple community partners. To establish a common foundation for the work of each subgroup, UNC and Partnership staff designed and facilitated a special session for Collaborative members to tell their personal stories about experiencing or participating in racism in the local healthcare system.

STORY TELLING SESSIONS

The full Collaborative participated in a structured story telling exercise to explore and understand collective and individual experiences with racism in the healthcare system (Figure 1). Five mixed-race, small groups were facilitated by UNC and Partnership staff in completing three rounds of discussion, one for each life stage. African American members were asked to complete the statement for each life stage, "As a [kid, teen, adult], I experienced racism in the healthcare system when…" White members were asked to complete the statement for each life stage, "As a [kid, teen, adult], I participated in racism in the healthcare system when…" These sensitive discussions enabled each Collaborative member to use the common language and framework from the Undoing Racism training to increase collective understanding and awareness of issues related to race, racism and power. Flip chart notes were analyzed and generated three themes: (1) lack of common history between African Americans and Whites influences the culture of healthcare, (2) healthcare lacks a system of accountability to address racism, and (3) negative experiences that African Americans often encounter within the healthcare setting include being disrespected, disbelieved, and dismissed.

A. When introducing the **"I remember <u>experiencing</u> racism within the health care system when…"** or (for members of the system) **"I remember <u>participating</u> in racism within the health care system when…"** exercise, components of the health system include:

a. ambulance, pre-hospital emergency services
b. health department
c. private doctor's office
d. health clinics
e. hospital
f. emergency room
g. dentist
h. prenatal care services
i. and others (presented by the group during the exercise)

Attempt to make multiple passes (up to 4) around the group for responses to the statement(s).

B. Record key phrases on the flip charts

Example:

<u>WHO</u>	**<u>WHAT HAPPENED</u>**	**<u>WHY?</u>**

(NOTE: In case the "WHY" is not filled, go back again to these examples at the end (in the last 10 to 15 minutes) and ask the individual or the group collectively, for thoughts/reflection for the "WHY?")

FIGURE 1. Activity instructions for storytelling capacity building workshop.

CBPR AND DEVELOPING THE CCARES RESEARCH QUESTIONS:

To develop the research questions, ten members of the Research Question Subgroup met four times. Since the request for proposals was for exploring racial disparities in healthcare, the discussions within the group were somewhat focused from the start. It was first necessary to explain the meaning of research questions with measurable objectives with members of the Research Question Subgroup. With months of previous team building the identification of the research question moved quickly and with little conflict. The information gathered from the story telling sessions, initially provided the basis for the content of the research question discussion and design. Existing expertise on cancer (and specifically breast cancer treatment) within the Subgroup facilitated the decision to focus on the following research questions: (1) Are there deviations in reasonable breast cancer care that are influenced by a patient's race? (2) If present, what factors contribute to the deviations from reasonable breast cancer care among African American patients? and (3) Do protocols exist to reduce deviations from reasonable breast cancer care that measure quality of the care offered and identify and pursue dropouts from the breast cancer care continuum?

CBPR AND DEVELOPING THE CCARES METHODOLOGY:

To determine the appropriate study design and data collection methods to investigate the research questions, eight members of the Methodology Subgroup met three times. The decisions drew heavily on the research experience of the medical/health professional members with different designs and methods. Community members weighed in on the critical internal validity issues of authenticity and trustworthiness of the different methods considered, ethical issues with regard to recruitment of participants, incentives, community concerns about research. It was this iterative process of critiquing multiple methodologies that led us to propose a mixed methodological approach for characterizing patterns of deviation from obtaining reasonable breast cancer care (cancer registry extraction and review) and exploring (critical incident interview with White and African American patients) the complex interplay of organizational factors that may have an adverse impact on breast cancer treatment and continuity of care for African American women.

CBPR AND THE CCARES ANALYSIS AND DISSEMINATION PLAN:

To develop a plan for analysis and dissemination, seven members of the Analysis and Dissemination Subgroup met twice. This phase was conflict free and moved rather smoothly. This Subgroup deliberated on how, where, when and who should be responsible for posting, electronically and by hard copy, updates on the project on a rolling basis through individual outreach efforts of Collaborative members, community CCARES health forums, Grand Rounds sessions at the cancer center, independently organized meetings and information sessions, and a quarterly newsletter.

CBPR AND THE CCARES READING AND REVIEW:

To review, edit, revise and ultimately approve the CCARES proposal, nine members of the Proposal Reading Subgroup met twice in person, and email was the primary form for exchanging comments, feedback, and subsequent revisions. A key challenge was to create a document that would convey the aims and goals of our effort to "outsiders," such as NIH and members of the local healthcare system, while effectively representing the knowledge, perspective and training that each member of the Collaborative had gone through to explore the dynamics of health in relation to institutional racism and the culture of healthcare institutions. Achieving consensus on language with which everyone was comfortable, therefore, added to the intense pressure from a rapidly approaching submission deadline.

CBPR AND DEVELOPING THE BUDGET:

Five members of the Budget Subgroup met a total of two times to develop an overall two-year budget and sub-contract with budget justifications, based on the decisions made by the other Subgroups. However, prior decisions made between UNC and The Partnership Project, regarding UNC serving as the fiscal agent for CCARES and the employer of the proposed Project Coordinator, were made

without adequate discussion with the Budget Subgroup. This serious lapse in communication occurred one month before the submission deadline, in large part due to delays in finalizing the study design and methods. This failure to communicate and engage the Budget Subgroup culminated in an extremely volatile situation, which fractured the Collaborative and disrupted the process of building trust. As a result, one medical/health professional member of the Budget Subgroup withdrew from the Collaborative. Although the conflict was managed by the full Collaborative as quickly and respectfully as possible, this single event has left a lingering sense of unease and distrust toward the UNC partners.

DISCUSSION

Our Collaborative's process of integrating CBPR principles with the Undoing Racism process presented four unique challenges that were accommodated and managed by creating a foundation of transparency and trust that viewed conflict as necessary. The process of developing the CCARES proposal illustrated a variety of important lessons about the challenges of necessary conflict.

One challenge is sustaining long-term involvement with representatives from all sectors, including the community, academic, and institutional sectors. Attrition and fatigue of 18 months of organizing and preparation ultimately resulted in some members leaving and coming back, some new members joining, and some unfortunately leaving permanently. A second related challenge is the establishment of a shared vision, when the Collaborative was faced with waning participation from some members and the introduction of new members who joined the Collaborative after the unique relationship building process had been cultivated from countless hours of meeting, sharing, arguing, and learning.

A third challenge is miscommunication through inaction, as the Collaborative experienced through the delay in working on the budget for CCARES. A fourth related challenge involves cultural differences which exist among the culture of research, the culture of program planning, and the culture of community. These differences were most palpable when the CCARES process was most at risk for moving out of the community representatives' control.

To accommodate and manage these challenges, an eclectic combination of skill, experience, and passion has made our development, preparation and submission of a successful NIH application for funding possible. By coming together as a learning-by-working group, our Collaborative has spent 18 months together, developing habits of speaking and listening to one another in ways that respectfully considered and moved beyond traditional roles of, for example, "medical professional" and "community member". Committing to six months of establishing a common language and collective understanding of institutional racism, which was often different from many members' own understanding, became a shared working analysis for the Collaborative. Committing eight months to learning CBPR principles and applying this new paradigm together to the CCARES proposal was essential to the Collaborative's exploration of how the system of cancer care works, understanding and framing our cultural differences, and negotiating conflict. We have struggled to change our deeply inculcated habits of perception. Part of the power of these habits was each member's ability to reassert perceptive differences at any time, but the "groupness" of our Collaborative enabled

individuals to check, challenge, and support each other's perceptions in the process of developing our grant application.

RECOMMENDATIONS AND CONCLUSION

Pertinent to integrating the processes of CBPR and Undoing Racism are the concepts of "cultural humility," which is the process of ongoing self-reflection and critique,[9] and "cultural safety," which is the premise that cultural factors have a major influence on the relationship and power between health professionals and community.[10,11] Although a collective belief in the motivations and sincerity of our members was apparent, there have been issues which have been described earlier, that have threatened the level of trust within the group. When the "power to plan" moves out of the hands of the community and into the hands of professionals or researchers, the cultural humility and cultural safety that has been so carefully cultivated can be easily violated. The reaction of community partners in research is often, "there they go again!" Extra vigilance to be entirely transparent in all decision making, despite timeline constraints, deadlines and expectations is continually needed. Short-cuts in communication should be avoided at all costs as this can create feelings of alienation and distrust, by both community and institutional partners, creating a climate that is not "safe," open and just.

Expecting, embracing and negotiating dynamics of conflict were essential in the process of inspiring, preparing and submitting our NIH application. Essential to negotiating these and other challenges has been the utilization of a CBPR approach. It is our hope that sharing the dynamics of our thoughtful, transparent, time and energy intensive process will assist and support other collaboratives' efforts to identify and successfully acquire funding using CBPR.

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